

**STRATEGIC
OBJECTIVE**

5

Understand the Factors that Influence Cancer Outcomes

We will support and conduct studies to increase our understanding of and ability to measure the environmental, behavioral, sociocultural, and economic influences that affect the quality of cancer care, survivorship, and health disparities.

It is critically important to advance a comprehensive, interdisciplinary research agenda to promote high standards of care, support reduction of the adverse effects of cancer diagnosis and treatment, and improve outcomes for all patients. Outcomes research describes, interprets, and predicts the impact of various influences on “final” endpoints that matter to decision makers, including patients, providers, private payers, government agencies, accrediting organizations, and society at large. These influences affect the extent to which public health programs and healthcare providers adopt recommended interventions, how successful the interventions are in addressing public health concerns, and how well patients adhere to provider recommendations. Outcomes may be measured in terms of survival, health-related quality of life, satisfaction with care, the performance of the health care system, and the economic burden on individuals or society.

NCI will support and conduct research to improve outcome measurement, expand access to data, and understand the influences on cancer outcomes and access to care. We also need to understand the barriers to dissemination and adoption of proven interventions in prevention, detection, diagnosis, and treatment. We must determine the best approaches to increase the use of evidence-based cancer interventions in public health and clinical practice and how best to use knowledge gained from research results to influence cancer policies.



STRATEGY 5.1—Develop standardized measures of cancer care outcomes across the cancer continuum.

Research to identify and standardize measures is needed to support the creation, evaluation, and implementation of novel interventions to improve cancer outcomes. Toward this end, we will:

- > Support the development of surrogate endpoint biomarkers that detect events in molecular pathways integral to cancer prevention and early detection—e.g., biomarkers for accurate and efficient assessment of patient risk and drug efficacy in prevention clinical trials.
- > Support research that identifies unwanted variations in patterns of care and enables us to better target quality improvement initiatives across the cancer care continuum.
- > Develop psychometrically valid measures to characterize patient-practitioner interactions and thereby assess and improve these relationships.
- > Develop informatics-based measures that allow clinical trials researchers and healthcare providers to monitor, recognize, and respond to patients' needs related to their functioning, symptoms and side effects, and health-related quality of life.
- > Develop new partnerships with Cancer Centers, professional societies, and research consortia to support the development, testing, and implementation of evidence-based outcome measures.
- > Identify measures specific to health disparities in cancer care and evaluate the effectiveness of screening, prevention, and treatment interventions intended to reduce those disparities.

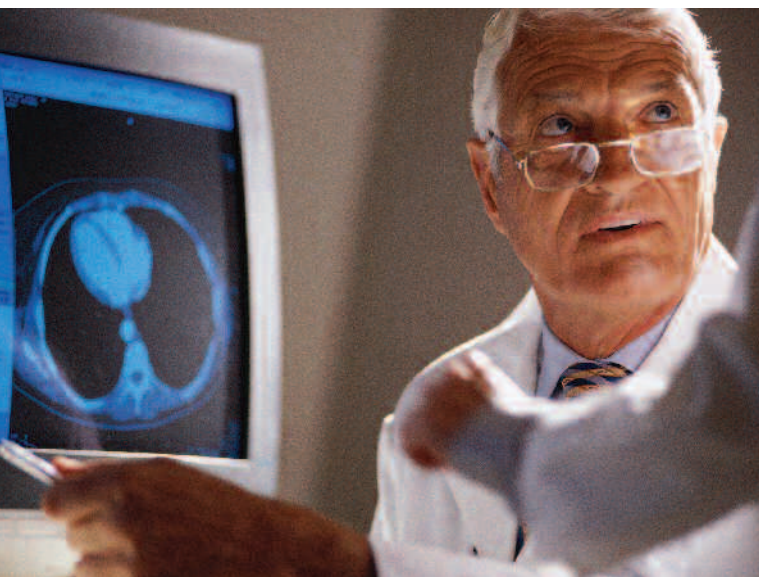
Final endpoints, such as survival, health-related quality of life, and societal economic burden, are distinguished from intermediate endpoints, such as rate of detection of early stage breast cancer, or clinical endpoints, such as degree of tumor shrinkage. Intermediate and clinical endpoints are critically important to the evaluation of an intervention.

STRATEGY 5.2—Identify research databases to study influences on cancer care and outcomes.

Epidemiologic surveillance helps investigators identify and characterize types, determinants, and outcomes of cancer and its treatment among various population groups. The combined use of cancer surveillance databases and electronic health records will deepen our understanding about what contributes to high quality cancer care from both biomedical and patient reported perspectives, taking into account ethnicity, socioeconomic status, and other demographic characteristics. NCI will:

- > Develop partnerships to link key data sources that track information on prevention and treatment interventions with NCI's surveillance programs to provide better insights into patterns of care and patient outcomes in the general population.

The NCI National Clinical Trials Program provides an avenue for deepening our understanding of what contributes to high quality cancer care from both biomedical and patient reported perspectives. By incorporating health-related quality of life endpoints into clinical study design, we can assess the effectiveness of specific treatments and their influence on the quality of life for patients and survivors.



- > Support development of tools for clinical modeling, evaluation, and cost-effectiveness and cost-benefit analyses of interventions that will ultimately assist care providers in advising patients about their care options.
- > Support collection and analysis of detailed patient reported data to identify determinants of health care quality, trends, and the ability of delivery systems to foster positive outcomes related to quality of life, including body image, sexuality, fertility, and any physiologic late effects including second cancers.

Patterns of Care Tell a Story of the Patient Experience

The most favorable outcomes for cancer patients can be achieved only when cancer treatments of proven efficacy are effectively delivered in the general community. NCI draws from the Surveillance, Epidemiology, and End Results (SEER) registry data to investigate the adoption of recommended treatments for the most common cancers. Studies linking SEER and Medicare data continue to provide insights in the quality of care across all populations.

In addition, NCI has established large national-level studies that track patterns of care and outcomes for cohorts of newly diagnosed cancer patients. The first of these, the Prostate Cancer Outcomes Study provided a wealth of information about treatment outcomes for 3,500 men diagnosed with tumors confined to the prostate gland. Another large study, the Breast Cancer Surveillance Consortium investigates factors associated with high-quality screening mammography in community practice. Evidence from a study involving over 300,000 women, including 2,200 women with cancer, examined the combined and individual effects of breast density, age, and hormone replacement therapy on the accuracy of screening mammography. The results of these patterns-of-care studies are reported at professional meetings of oncology societies and are used to develop educational and training opportunities to improve the use of state-of-the-art cancer therapy in community practice.

STRATEGY 5.3—Increase the understanding of behavioral and sociocultural factors that influence cancer outcomes.

Integrating social, psychological, and communications research with biological research significantly improves our understanding of these factors and their relationship to disease prevention, quality of cancer care, and health outcomes. NCI will:

- > Develop population-based data sets and complementary quantitative and qualitative research studies to better understand the relationships between behavioral risk factors and their impact on cancer incidence, prevention, quality of cancer care, survivorship, and health disparities.
- > Promote strategic partnerships to study factors that influence health outcomes by examining traditional evidence-based systems and approaches as well as alternative and complementary medicine components of the cancer care delivery system. For example, we will support

interdisciplinary research on the adverse effects of cancer treatments, including identifying markers of susceptibility to these effects and gene-environment interactions.

- > Conduct and support research on how social and psychological factors affect health communications and patient-provider decision making, and how race, ethnicity, literacy, and socioeconomic status influence these interactions.
- > Collaborate with others to synthesize research with respect to the role of sociocultural, behavioral, emotional, and spiritual factors that affect patients' treatment and follow-up and health maintenance behaviors following treatment.
- > Establish partnerships for and support community-based and health care delivery research to translate findings into policy to improve the quality of care and reduce cancer health disparities.

The Interface of Biological and Behavioral Sciences

NCI supports and evaluates a comprehensive program of research to increase the quality of cancer prevention and control through the behavioral sciences. This includes the integration of genetic, epidemiological, behavioral, social, applied, and surveillance cancer research. This research is aimed at identifying the theoretical underpinnings of cancer-related behavior and behavior change across all ages, racial and ethnic groups, socioeconomic strata, and cancer diagnoses. For example, NCI supports research on cognition, emotion, stress, and pathways to health outcomes; links between education and health; social and cultural determinants of health; and mind-body interactions and health.

New interventions must be firmly grounded on scientific evidence, especially the findings that result from epidemiological and surveillance research. Epidemiological research is essential to assess the weight of evidence for particular cancer risk-reducing behavioral recommendations. Surveillance research and its application tells us where we are in our progress against cancer, generates hypotheses for more basic research and interventions, and provides important data for understanding the role of health services and policies on cancer outcomes. Research in epidemiology, cancer-related behaviors, and surveillance should be woven together inextricably to optimize progress in the control of cancer.

STRATEGY 5.4—Increase our understanding of the factors that affect access to cancer care.

Disease always occurs within the social context of human circumstances, including social position, economic status, culture, and environment. To understand cancer incidence and outcomes, we need to understand the context in which they occur. NCI will:

- > Partner with other Federal agencies, universities, the private sector, and local communities to support transdisciplinary research to identify barriers that prevent many people from receiving the best quality care and obtaining the best outcomes. This research will address systemic barriers such as fragmentation of care; financial barriers, including lack of health insurance or underinsurance; physical barriers such as distance to treatment facilities; knowledge, language, and education barriers for both patients and providers; and issues of culture and bias, both personal and institutional.
- > Investigate factors that hinder people from participating in clinical trials of cutting-edge, state-of-the-science treatments.



- > Support participation in clinical trials through patient outreach, recruitment, and retention, especially in underserved populations.
- > Investigate the economics of access to care by studying the comparative costs of reducing delays in patient diagnosis and receipt of follow-up care after abnormal findings, the comparative costs of treating specific cancers at an earlier rather than later stage of disease, and the cost-benefits of reducing cancer morbidity, mortality, and health disparities.



STRATEGY 5.5—Build sustainable community-based structures to support research on cancer outcomes.

Knowledge about what constitutes quality cancer care, how well it is being delivered, and what needs to be done to overcome inequalities and associated disparate outcomes resides within the communities where services are provided. NCI will:

- > Support community-based research to include the perspectives of the patient or consumer and that of the healthcare provider to expand our understanding of cancer care generally and health disparities in particular.
- > Support community-based research partnerships that generate better informed hypotheses, develop more effective interventions, and enhance the translation of research results into practice.

STRATEGY 5.6—Expand our understanding of how to disseminate research results and promote the adoption of evidence-based cancer interventions by a diverse population of patients, providers, and the public.

As new investments in basic and translational research close the gap between discovery and development, equally important is the need to close the gap between development and delivery. Doing so will require research to develop more effective methods for disseminating